A GUIDE FOR HARD TIMES

For caregivers — everything I wish I had known in the first week

I wrote this for my own family, during a stretch when I had no idea which way was up. I have stripped out everything personal and I am leaving it here, in case it helps someone who is just walking into this.

There is nothing revolutionary in it. It is just everything I wish someone had written down for me, instead of me searching on my phone at 3am.

🌍 WRITTEN IN ROMANIA — READ THIS BEFORE YOU USE IT

This came out of one healthcare system. Some of it will not transfer. The honest version:

The emergency number here is 112.
Yours is probably different — 911, 999, 000, 119. Find it, write it down, put it on the fridge. Do not assume the number in a guide from another country is your number.

Half of this guide is a workaround for a system that coordinates nothing.
Here, you carry your own records. Nobody assembles them for you. That is why I am obsessive about photocopies and binders. If your system has a patient portal, a records department, or a care coordinator who does this — skip those parts. You do not need my binder.

We had nobody guiding us. You might.
This guide never mentions patient navigators, oncology social workers, palliative care teams, or district nurses — because we did not have them. If your system does, they are better than anything in this document. Ask for them by name, early, and use them.

Referrals, health cards, and paperwork are local.
Whatever I say about documents, translate it into your own system's equivalent — or ignore it.

What does transfer:
The warning signs. The questions to ask a doctor. The medication table. The bland food. The mobilisation. The panic attack steps. The part about looking after yourself. Bodies and fear are the same everywhere.

HOW THIS IS ORGANISED

🔴 NOW	🔵 DAILY	🟢 FOR YOU
Emergencies. Section 1.	The routine. Sections 2–13.	The caregiver. Sections 15–16.

⚠️ READ THIS FIRST

I am not a doctor. This guide is about organisation, not treatment.

I deliberately removed every drug name. They were prescribed for one man, with one condition. What worked for us could hurt someone else.

1. **Nothing goes in the mouth without asking the doctor or pharmacist.** Including teas. Including "but it's natural".
2. **Teas and supplements are drugs.** They interact with what the person is already taking.
3. **If you have a medical question, the answer is not in here.** It is with the treating doctor.

🔴 NOW

1 Warning signs

This is the page for the fridge. The rest of the guide is for the good days.

☎️ Call emergency services now

💔 **Chest**	Chest pain or pressure. Pain spreading to the arm or jaw.
🫁 **Breathing**	Struggling to breathe. Blue lips or fingers. Cannot finish a sentence.
🧠 **Brain**	Sudden confusion. Slurred speech. One side of the face drooping. Sudden weakness on one side.
😶 **Consciousness**	Fainting. Seizures. Unresponsive.
🩸 **Bleeding**	Bleeding that will not stop. Blood in vomit. Black tarry stools.
🌡️ **Fever**	High fever in someone on chemotherapy or immunosuppressed. This is an emergency, not a "we'll see tomorrow".
🤕 **Falls**	A fall with a head injury — especially on blood thinners.

📌 **Write your emergency number here. Now, before you need it.**

Emergency: .....

📞 Call the treating doctor the same day

- Not passing urine, or passing very little
- Vomiting that will not stop — cannot even keep water down
- More than 3 days without a bowel movement **plus** pain, or a swollen hard belly
- A new, painful swelling in one leg
- Mild confusion, unusual drowsiness
- Any new reaction after a new medication

📌 **Keep the numbers written on paper, stuck to the fridge. Not just in your phone.**

The phone dies exactly then.

Treating doctor: .....

Ward / hospital: .....

Family doctor / GP: .....

Pharmacy: .....

Out-of-hours service: .....

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2 The medical file

> 🌍 **Local note**
> Where I live, you carry your own records — nobody assembles them for you. If your system has a patient portal or a records department, most of this section is already done for you. Read it as a checklist of what should exist somewhere, not as work you must do.

What goes in it

- ID and any health insurance card
- All recent results: bloods, imaging, scans, pathology reports
- Referral letters
- **2–3 sets of photocopies** — people will ask for them and will not give them back
- An up-to-date list of medications and supplements, with doses and times
- History: surgeries, allergies, previous admissions
- Contacts: family doctor, every specialist, pharmacy, ward
- A notebook for daily observations and questions

> 💡 **What I would do differently from day one**
> Scan everything to your phone, into one folder, as it arrives. At some point a doctor will ask "what was the March result?" and you will be standing in a corridor without the binder.

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3 Questions for the doctor

You forget everything once you are in the room. Write them down beforehand, on paper, and tick them off.

🔍 About the diagnosis

- What exactly is it called? Could you write it down for me?
- What stage are we at, and what does that mean in practice?
- What tests are still missing before a decision?

💊 About treatment

- What are the options — not just the recommended one?
- What happens if we do nothing?
- What is the goal: cure, control, or comfort?
- Which side effects are common, and which ones mean I call you immediately?
- How long does it last, and what does an ordinary day look like during it?

🏠 About daily life

- What can he eat? What must he avoid?
- Can he keep taking what he took before? (show the full list, supplements included)
- How much can he move? Can he drive?
- What do I do if something happens at night or at the weekend?

📋 Practical

- Who is my point of contact between visits?
- What is the next concrete step, and when?
- Is there a second opinion you would recommend?
- **Is there a patient navigator, social worker, or palliative care team I should be talking to?** — we did not have this. If you do, it changes everything.

> **🎙️ Ask permission to record the conversation on your phone.**
> Most doctors say yes. You will not remember a word of the first ten minutes after bad news.

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4 The two bags

🎒 Admission bag — for him

Keep it packed, by the door. When it happens, you will not have the head to pack it.

🪪 **Documents** ID, insurance card, referral	📄 **Results** Recent ones + 2–3 copies	💊 **Medication** The list, with doses and times
👕 **Clothes** Pyjamas, underwear, slippers, towel	🔌 **Power** Phone, charger, extension lead	📖 **Time** Book, puzzles, notebook, pen

🧰 Companion bag — for you

Nobody tells you that you will spend six hours in a corridor.

📁 **Paperwork** The file + copies + your question list	💵 **Cash** For emergencies	🔋 **Power bank** Plus charger and extension lead
🥪 **Food** Something that keeps. Water.	🧴 **Hygiene** Hand gel, wipes, spare mask	💊 **Yours** Your own regular medication
🧣 **Blanket / scarf** Waiting rooms are cold	🎧 **Headphones** Or earplugs. For quiet.	🚗 **A plan** Who takes over, who drives

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5 Appointments and scans

> ⚠ **The real instructions come from the clinic.**
> They vary by centre and by protocol. Do not follow a template off the internet — ask wherever the appointment is booked.

Fill this in for each scan

Scan	Date / time	Location	Preparation	Who takes him

✅ What I learned

- Call the clinic two days before **and ask for the preparation again, out loud.** It changes.
- Ask explicitly: does he eat or not? Does he take his morning medication or not? **For diabetics, that question is critical.**
- If contrast is involved, tell them about allergies, kidney disease and current treatments. **Before, not during.**
- Arrive 30 minutes early. Always.
- Ask when **and how** you get the result. Otherwise you wait two weeks for nothing.

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6 Medication tracker

> **This table was the single most useful thing in the whole document.**
> When three different doctors each add something, only this piece of paper knows the truth. Take it to every appointment. Photograph it.

Medication	Dose	Time	With / without food	Since	Who prescribed it	Effects noticed

💡 *The "who prescribed it" column looks pointless until a doctor asks "who put him on that?" and nobody knows.*

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7 Bland food

> ⚠ **Check with the doctor. Some diets (renal, diabetic, post-surgical) rule out things below.**

✅ Works

🥣 **Soups**	Plain vegetable, strained. Creamed carrot and celeriac, or pumpkin.
🥔 **Purées**	Courgette. Cauliflower with carrot. Carrot with sweet potato.
🍚 **Grains**	Semolina with water or plant milk. Rice pudding. Fine oats. Soft pasta.
🥔 **Potatoes**	Plain boiled with parsley. Baked sweet potato with a little olive oil.
🍎 **Fruit**	Baked apple or pear. Apple and quince compote. Banana simmered in water.
🍳 **Protein**	Steamed omelette. Gradually move to chicken or fish — steamed or boiled, never fried.
💧 **Special**	Rice water — for an irritated stomach and loose stools.

🚫 Avoid

☕ **Coffee**	Strong, or on an empty stomach — irritates, agitates, raises blood pressure
🍟 **Fried food**	Hard to digest, reflux
🧀 **Fatty dairy**	Aged cheeses — ferment in the stomach
🧂 **Salt**	Cured meats, pickles
🥤 **Fizzy drinks**	Shop-bought juices — bloating
🍬 **Sweets**	Processed, chocolate
🍛 **Heavy sauces**	Mayonnaise, ketchup
🍅 **Raw**	Raw fruit, raw tomatoes — acidic, ferment
🥫 **Ultra-processed**	Tinned pâté, margarine, snacks
🥖 **White bread**	Fresh, doughy — fermentation
🫘 **Pulses**	Beans, dried peas
🥦 **Raw brassicas**	Cauliflower, broccoli, cabbage, peppers — gas

> 💡 **What I learned about appetite**
>
> - Small and frequent beats large meals.
> - A full plate put in front of someone is discouraging. Half a plate, six times a day, works better.
> - **Do not push.** Pushing turns a meal into a fight.

🔵 DAILY

8 Herbal teas — carefully

> 🌍 **Local note**
> Herbal tea is a big deal where I am from — every pharmacy sells it, every grandmother recommends it. If that is not your culture, you may not need this section at all. The interaction warnings still stand wherever you are.

> **This is the part where I wish I had known more.**
> Herbal teas are not "just water with plants". Some interact seriously with medication.

⛔ These NOT without explicit medical approval

🌼 **St John's wort**	Lowers the blood concentration of a very long list of drugs: chemotherapy agents, blood thinners, antidepressants, immunosuppressants, contraceptives. It can stop a treatment working. The most dangerous "harmless tea" on the shelf.
🍂 **Buckthorn, senna**	Stimulant laxatives. If the constipation has an obstructive cause, they can be dangerous. They also cause dependence.
🍭 **Liquorice root**	Raises blood pressure, lowers potassium. Bad if there is dizziness or hypertension.
🌿 **Ginger, hibiscus, hawthorn**	Can interfere with blood thinners and blood pressure medication.

✅ Generally gentle — but still ask

🌿 **Chamomile**	Settles the stomach, helps sleep
🌸 **Linden**	Relaxing
🌼 **Calendula**	Anti-inflammatory for digestion
💜 **Lavender**	Reduces anxiety
🌱 **Mint**	Nausea, bloating. Careful: worsens reflux, can slow transit.
🌿 **Basil**	Gentle on the stomach

> 📌 **The simple rule**
> - Warm, not hot.

- Do not combine several without asking.
- Write them on the medication list. **They are medication.**

🔵 DAILY

9 Movement and dizziness

🧍 Getting him moving

The part everybody skips and the one that matters most. Lying in bed wastes muscle faster than you think — and that is where the falls come from.

🪑 **3× a day** Sitting up 10 min, back supported	🚶 **Walk** 5–10 min around the house, even with support	🔄 **Joints** Ankle, arm, shoulder circles — daily
🌞 **Daylight** 10–15 min in the morning	🫁 **Breathing** Deep, a few times a day	💧 **Water** Constant, in small sips

> 💡 **Ask for a physiotherapist. Seriously.**
> Even one session, to show you how to get someone up safely and what can be done in bed. It is the most underused thing in the entire system.

🌪️ Dizziness — the plan

> ⚠ **New or worsening dizziness goes to the doctor.**
> It can be blood pressure, dehydration, anaemia, a new drug, or something else. The plan below is for dizziness a doctor has already assessed and explained — not for new dizziness.

Getting out of bed, in stages

4. Gentle movement in bed first — ankle circles, fists, leg movements
5. Roll onto one side
6. Push up to sitting
7. **Sit on the edge of the bed for 1–2 minutes**, feet on the floor
8. Only then stand, with support

The rest of the day

- No sudden position changes and no effort straight after standing
- Compression socks in the morning, if the doctor agrees
- 4-7-8 or 4-6 breathing
- A gentle walk or time in fresh air, 5–10 min
- Evenings: soft light, quiet activity. No screens, no news, no tense conversations.

> 🏠 **At home: take up the small rugs. Night light on the way to the bathroom. Grab rail in the bathroom.**
>
> Most falls happen at night, on that walk.

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10 The bowel plan

It is not a joke and it is not embarrassing. It is one of the most common problems and one of the biggest destroyers of quality of life.

> ⚠ **First ask the doctor why he is constipated.**
>
> It might be opioids, lack of movement, dehydration — or it might be something that gets worse if you give a laxative. If he is on opioids, the laxative is given preventively, not once the problem appears.

🕗 The gentle morning routine

9. **On waking:** a spoonful of cold-pressed oil on an empty stomach
10. **After 10 minutes:** 2–3 spoons of mashed baked apple or courgette purée
11. **After another 10–15 minutes:** a few sips of weak, diluted coffee — only if there is no heartburn or nausea. Chicory or roasted barley works as a gentler substitute.
12. **Throughout:** room-temperature still water, in small sips
13. **If he can:** a short walk, or movement at the edge of the bed

What helps in the background

- Hydration, movement, soluble fibre (baked apple, oats, courgette)
- **The same time every day.** The body learns.

> 📞 **More than 3 days without a bowel movement + pain or a swollen belly → call the doctor.**
>
> Stop trying remedies.

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11 Distraction

The day is long and fear has time to settle in. These worked for us.

📺 **Easy series**	Episodic comedies. No tension, no cliffhangers. The point is to be able to fall asleep halfway through and miss nothing.
📖 **Light books**	Short stories, illustrated books, anything with a happy ending. Audiobooks when the eyes get tired.
🧩 **Puzzles**	Sudoku, crosswords. Occupies the mind without effort.
🎧 **Sound**	Forest, rain, waves, sleep music.
🗣️ **Conversation**	About memories, not about the illness. "What was your favourite holiday?" Sick people get tired of being asked how they feel.
🌞 **Window or balcony**	10–15 minutes of daylight and air.
🚶 **Walk around the house**	Even 2–3 minutes. It gives back a sense of control.
🪞 **Small self-care**	Washing his face, doing his hair, nice-smelling cream. The signal that the day counts.
🫁 **Guided breathing**	4 seconds in, 4 hold, 4 out. Can be done in bed.
📓 **One-line journal**	"Today what made me smile was..."
🙏 **Prayer or a phrase**	If he is a believer, it helps enormously with the hard bits: standing up, the walk to the car, the waiting. Do not underestimate it.

🔵 DAILY

12 The shape of a day — example

Do not copy it. Adapt it. The point is for the day to have a shape, not for him to tick boxes.

On waking	Movement in bed → getting up in stages → the bowel routine
Early morning	Baked apple or purée. Medication as per the table.
Morning	Daylight 10–15 min. Washing, cream, getting dressed.
Mid-morning	Sitting up 10 min. Small snack + water.
Lunch	Bland meal, small portion. Warm tea.
After lunch	Rest. No screens.
Afternoon	Walk around the house 5–10 min. Quiet activity.
Early evening	Sitting up 10 min. Light meal, early.
Evening	Soft light. No news, no tense conversations. Breathing.
Night	Water within reach. Night light to the bathroom.

> 📌 **The three non-negotiables**
>
> - Medication at fixed times
> - Water
> - The three times out of bed
>
> *Everything else is a bonus.*

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13 Daily log

Thirty seconds in the evening. Take it to the doctor.

It is worth more than "I think he's been a bit rough for a couple of days". Use a 1–5 scale for sleep, appetite and mood. Do not overcomplicate it. Under "Notes", write only what is new.

Date	Bowels	Sleep 1–5	Appetite 1–5	Mood 1–5	Activity	Notes

🔴 NOW

14 Panic attack

"What you feel right now is real, but it passes."

> ⚠ **The first time it happens, see a doctor.**
> Chest pain and breathlessness can also be the heart, the lungs, or a clot. "It's just panic" is a diagnosis a doctor makes — not you, and not the first time.

1️⃣ **Name it**	"This is a panic attack. It will pass. My body is reacting, but I am safe."
2️⃣ **Breathe**	In for 4 → hold 4 → out for 6. Repeat 5–10 times. The longer out-breath is the key — it switches on the parasympathetic system.
3️⃣ **Grounding**	5 things you can SEE · 4 you can HEAR · 3 you can TOUCH · 2 you can SMELL · 1 you can TASTE
4️⃣ **Physical input**	Something cold in the hand. Cold water on the face. Palms flat on a hard surface.
5️⃣ **The phrase**	"It is only anxiety. I am not fighting it. I am letting it pass."

🌿 Afterwards

- Rest 15–30 min
- Still water, no coffee
- Something light to eat

🧩 Prevention

- Regular routines — sleep, meals, movement
- Less caffeine, less news, fewer screens
- Gentle daily movement
- Talking to someone you trust

> **If it keeps happening, tea will not fix it.**
> A psychiatrist or therapist will. It is treatable and the treatment works.

🟢 FOR YOU

15 First aid for the caregiver

> **"Look after yourself so you can look after everyone else."**
>
> *I wrote this last and it should have been first. I ignored it for months and it did not go well.*

🚶 **Get outside** At least 15 min, even just around the block	🚿 **Shower** Changes the state, resets you	🥗 **Eat first** It sounds selfish. It is not.
💧 **Water** Every 2–3 hours	☎️ **Talk** To friends, regularly — not only in a crisis	🧘 **Small rituals** Music, a candle, 20 min with your eyes shut
🛌 **Scheduled rest** In the calendar, like an appointment	📔 **Write** Somewhere to put it down	🧩 **One thing for you** An episode, a page, a puzzle

🙋 Ask for help — but be specific

People genuinely want to help. They just do not know what to do.

✅ **"Could you sit with him Thursday, 4 to 6?" → works**

❌ **"Let me know if you need anything" → never works**

> ⚠ **If you stop sleeping, stop eating, or stop feeling anything — see a doctor.**
>
> Your exhaustion is a medical problem for the person you are caring for, too. Caregiver burnout is real, and it is a condition, not a weakness.

🟢 FOR YOU

16 What I would tell someone starting out

✍️	Write everything down. Your memory does not work in this period, however good it normally is.
👥	Take someone with you to appointments. Two people hear twice as much.
❓	Ask "what does that mean for us in practice?" after every medical term.
🌙	Do not look up survival statistics at 3am. That is not him — it is an average.
📋	Split the jobs in the family in writing, or one person ends up doing all of it.
💚	It is okay not to feel grateful for the experience. It is just hard.

> 🌍 **One last time: this was written in Romania.**
> Check your emergency number. Check what your own system already does for you before you rebuild it by hand. And if anything here contradicts your medical team — your medical team is right, not this document.